

MEDICAID MATTERS: JOIN NDSC'S ADVOCACY EFFORTS TO PROTECT MEDICAID

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Agenda

- Welcome
- NDSC's Policy Work
- Political Realities & Implications
- Medicaid Overview
- HR 1 – OBBBA (Reconciliation bill)
 - Key Medicaid changes
 - Work requirements
- What You Can Do
- Questions & Answers



NDSC's Policy Work

- NDSC is a nonpartisan 501(c)(3) nonprofit and does not have a political action committee.
- We do not get involved in elections, endorsements, or campaigns.
- We take positions on **policies not politicians**.
- We work in a bipartisan manner
- We regularly consult with our bipartisan Policy Advisory Council
- We collaborate with other groups and work in coalitions such as the United Coalition on Down Syndrome (UCDS), Consortium for Constituents with Disabilities (CCD), and the Collaboration to Promote Self-Determination (CPSD)

NDSC's only goal is to promote the interests of people with Down syndrome, their families, and others who support them so they can live meaningful, inclusive, self-determined lives.



Current Political Climate

- Government Shut Down
 - Minimal bipartisan cooperation, especially on healthcare, education, and civil rights.
- 119th Congress: gridlock on major disability-related legislation; appropriations battles still looming.
- Courts increasingly involved as agencies bypass normal rulemaking processes.
- Administration making quick and drastic changes without much stakeholder input and lack of transparency, and contrary to Congressional intent.

Administration Actions

- **Major restructuring of federal agencies**
 - Layoffs, furloughs & consolidation at HHS, Dept. Of Education, and other key agencies affecting disability programs
- **Rapid deregulation**
 - Use of executive actions and interim rules with no notice or public comment, impacting protections under ADA, IDEA, Medicaid, employment (14c) and Section 504
- **Legal challenges mounting**
 - States, advocacy groups suing over regulatory rollbacks that circumvent the Administrative Procedures Act (APA)

Implications for Disability Community

- We are playing DEFENSE in many different areas
 - Moving targets, lack of transparency, not following regular processes
 - Dramatic reduction of federal employees impacting many programs and PWD
- Traditionally bipartisan issues are getting swept up in partisan fights – must retain bipartisan support
- Telling your story is critical: many Members are unaware of impacts on PwD
- State level advocacy becomes more important

Medicaid:

A Lifeline for People with Disabilities

- **Covers 83 million people:** 17 million older adults & people with disabilities
- **More than medical care:** Covers vital home and community-based services (HCBS), personal care, and long-term supports
 - **Waiver programs under Medicaid:** Some examples - Medi-Cal (CA), HUSKY Health (CT), Healthchoice Illinois, MaineCare, MassHealth, NJ FamilyCare, Healthy Connections (SC), STAR(TX), Green Mountain Care (VT) and more...
 - **Longer Wait Lists:** over 710,000 people w disabilities waiting for Medicaid HCBS across the country
- **Supports schools:** Funds services like EI, habilitative services, speech and behavioral therapies
- **Federal share (FMAP):** traditionally 50–75%+, based on need
- **Without Medicaid:** Devastating out-of-pocket costs, risk institutionalization, loss of independence

Mandatory vs. Optional Benefits

- **Mandatory Benefits** (all states *must* cover):
Hospital & doctor visits, labs/X-rays, nursing home care, family planning, and EPSDT for children under 21
- **Optional Benefits** (states *may* cover):
Prescription drugs, dental, vision, mental health, personal care, respite, assistive tech, employment supports, transportation, and more
- **Home & Community-Based Services (HCBS)**
 - Optional, but critical for people with disabilities to live independently
 - States decide what to cover and who qualifies
 - When Medicaid is cut, HCBS are the first to go—has been shown in all 50 states
- Learn more: [medicaid.gov/medicaid/benefits](https://www.medicaid.gov/medicaid/benefits)



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H.R. 1 – OBBBA (Reconciliation bill)

- Signed into law on July 4, 2025
- Partial advocacy success in that we prevented some really terrible changes to Medicaid program (no block grants or per capita caps)
- Some positive provisions
 - HCBS Expansion – provides some funding to states for waivers
 - ENABLE Act – made permanent ABLE to Work, ABLE Rollover and ABLE Tax Savers Credit
- Rollout period for changes
- Makes distinctions between people on traditional Medicaid pathway and Medicaid expansion population
- ***HR1 will have negative consequences for people with disabilities, their caregivers, and entire Medicaid system***

HR1 Medicaid Changes

- **Deep cuts to federal Medicaid funding**
 - Total reduction: \$930 billion in federal Medicaid and CHIP spending over next decade (2025-2034)
 - Expansion states (41) hit the hardest; HCBS services at risk
- **Work requirements & eligibility hurdles**
 - Adults under 65 without exemptions must verify 80 hours/month or lose coverage
- **Stricter redeterminations and more paperwork**
 - Increased risk of coverage loss, even for some eligible people with disabilities (6-month redeterminations for Medicaid expansion population)
 - Will hit DSPs and direct care workers hard

HR1 Medicaid Changes (cont'd)

- **Cuts to retroactive coverage**
 - Retroactive eligibility shortened or eliminated (from 90 days to 60 for traditional Medicaid population)
 - Risk of major medical debt for people with disabilities or dual eligibles who need urgent care
- **HCBS**
 - States encouraged to shift to managed care and self-direction
 - Flexibility gives more autonomy but underfunding could shrink access and quality
 - Workforce instability likely without provider rate protections
- **Limitation on State Provider Taxes**
 - States must make up funding gaps other ways

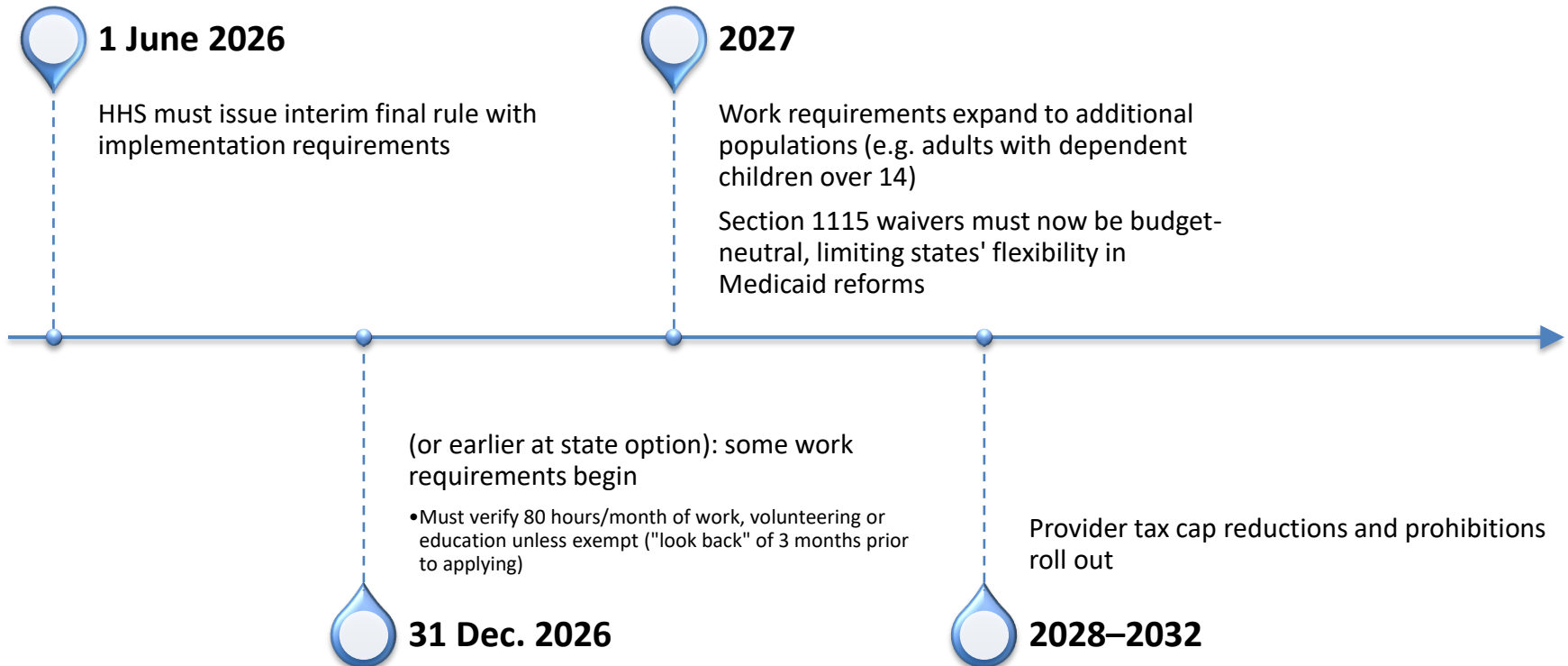
Work ("Community Engagement") Requirements

- **What are they?**
 - States are **required** to impose work requirements on certain Medicaid enrollees in order to maintain coverage
 - Limited to ***Medicaid expansion population***
 - Each month, the eligible individual must do **80 hours** of one (or combination) of the following – and prove compliance -- in order to receive Medicaid:
 - Work
 - School (at least half-time enrolled)
 - Community Service
 - Exemptions (may not be automatic)
 - People under age 19 or over 64
 - Pregnant women
 - Individuals who are "medically frail" (not yet defined)
 - Individuals with child or disabled dependents
 - Other hardships (e.g., hospitalization)
- **Rationale**
 - Supposed to promote employment and independence & reduce reliance on public programs

Work Requirements – What Actually Happens

- Employment does NOT increase
- Complex reporting systems lead to confusion and loss of coverage
 - In Arkansas, over 18,000 eligible people lost coverage in 7 months
 - In NH and MI, legal rulings ended work requirements programs
 - Tens of thousands of people were set to lose eligibility
 - GA still in place with very slow rollout
- Paperwork and administrative burdens
 - 6-month redeterminations will make it worse
- Exemptions may not be automatic
- States must by **January 1, 2027**

Timing of Key Provisions



Medicaid is MediCal...And so much more

- Medicaid funds (or partially funds)
 - Health care/secondary coverage/copays
 - CCS
 - IHSS
 - IEP services
 - School-based health care and screenings
 - Regional Center System
- [Undivided.io](https://undivided.io) has an amazing explanation for the HCBS-DD Waiver (we usually call this "Institutional Deeming Waiver")

Recent letter from DCHS: Do not panic

- People with Medi-Cal are starting to receive "assets" letters.
- This is not for the Medi-Cal Institutional Deeming (HCBS-DD waiver)
- HCBS-DD waiver in place (as is) until 2027

California Down Syndrome Advocacy Coalition

- Grassroots – Our goal is to connect all the Down syndrome orgs in California
- Focus on relationships around the state
- Policy not politics
- Representation on statewide coalitions/organizations/task forces
- California programs
 - Self Determination Program
 - Regional Center System
 - Housing
 - Employment
 - Education
 - Add your favorite unnamed area and join us!



What You Can Do: Pivot Medicaid Advocacy to the State Level

- **Influence the State Budget**
 - Build relationships with legislators and budget staff
 - Push for Medicaid to be a state funding priority
 - Advocate for general funds to fill federal funding gaps
 - Testify at hearings, submit public comments during budget season
- **Protect & Expand HCBS**
 - Defend HCBS waiver programs (1915(c), 1115)
 - Push for DSP rate increases to stabilize the workforce
 - Monitor waiver renewals and demand transparency

What You Can Do: Pivot Medicaid Advocacy to the State Level (cont.)

- **Safeguard Eligibility & Access**
 - Work with Medicaid agencies to track disenrollments
 - Ensure systems are accessible and errors are addressed
 - Push for simpler renewal and reinstatement processes
- **Engage in the Process**
 - Join advisory groups, review state plan amendments
 - Submit comments on proposed changes
 - Monitor and respond to federal rulemaking (e.g., HHS regs in 2026)

Gentle Reminder

- We are encouraging everyone to keep copies of all correspondence with anything related to Medicaid/Medicare
- HCBS or other Waiver
- SSI/SSDI
- Print materials from online account for records

What State and Local Governments Control

Health & Services: Medicaid eligibility, waivers, HCBS design, mental health, DSP wages, provider reimbursements

Education: Early intervention (Part C), special ed staffing/services, preschool & transition supports, discipline & accommodations

Disability Rights & Daily Life: Accessibility enforcement, housing supports, vocational rehab, guardianship & supported decisionmaking laws

Transportation & Inclusion: Paratransit, local transit, sidewalks, zoning, inclusive recreation



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Benefits of State Level Advocacy



States move more quickly

Legislatures meet for short time periods and move fast.
Change can happen within a single session or budget cycle.
Implementation periods tend to be shorter.



Better access to state level legislators

Less staff so more likely to meet in person.
They are part of your local community.
They often have other jobs and are in-district more.



States decide what services actually look like

They implement Medicaid waivers, special education supports, HCBS, employment services
The same federal law can look very different from state to state
States can innovate & model creative solutions



Can provide protection against federal rollbacks

States can counter harmful federal policy
State law can expand rights beyond minimum federal standards

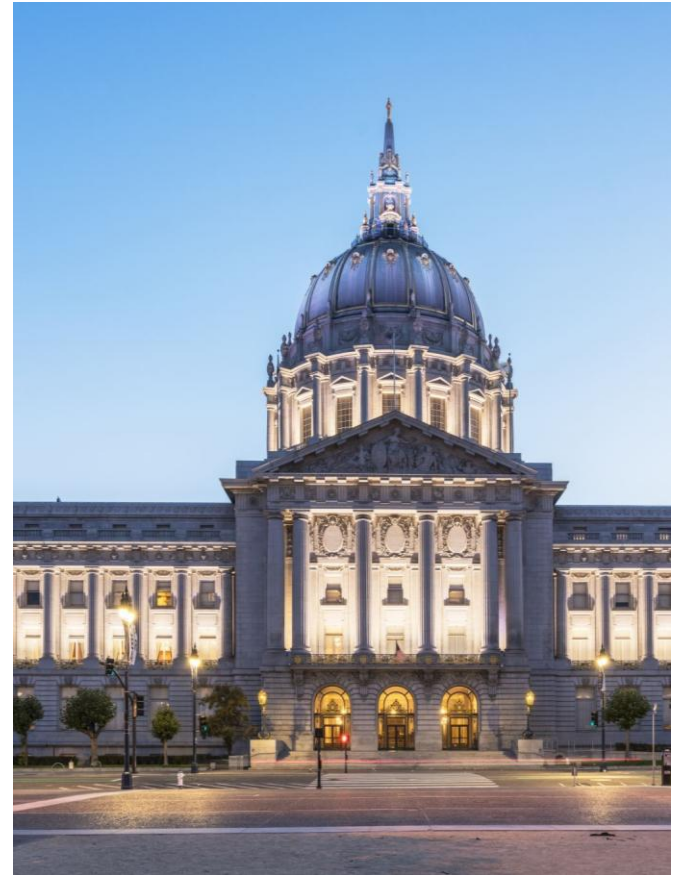
Ways to Engage in State or Local Level Advocacy

- **Build relationships, tell your story, stay nonpartisan and professional**
- **Engage in state legislative sessions**
 - Testify at hearings or submit written testimony
 - Show up at rallies, hearings
- **Mobilize local voices**
 - Organize advocacy days at your state capital
 - Empower self-advocates & families to speak out
 - Use social media, op-eds, town halls to reach lawmakers and the public
- **Watch budgets & waivers closely**
 - Monitor Medicaid waiver renewals & amendments
 - Advocate for state funding for services that may be cut federally
 - Push for re-investment of state surplus or rainy-day funds into disability services
- **Serve on issue-specific task forces, workgroups, advisory committees**
- **Submit comments, attend town halls**
- **Join or form coalitions (DS, cross-disability, civil rights)**

NDSC's State Advocacy Engagement Plan

Learn about your state legislature

- <https://www.congress.gov/state-legislature-websites>
- Length and dates of session
- Learn about your state legislators
 - <https://www.usa.gov/elected-officials>
 - Constituency is paramount
 - Are they in leadership positions?
 - Are they on key committees?
 - What are their main priorities?



State Advocacy Engagement Plan



Individual coalition-building and networking

Who are the other NDAC members in your state? Contact us to ask – policy@ndsccenter.org

Statewide DS or IDD coalitions? Cross-disability coalitions or workgroups?

SELF-ADVOCATES, SELF-ADVOCATES, SELF-ADVOCATES!



Opportunities for Learning, Outreach, and Partnerships

Partners in Policymaking

DD Day at your state legislature

UCEDD and LEND program

World DS Day

Public events (town halls, briefings, etc)



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STATE AND LOCAL ADVOCACY TOOLKIT



COMING
SOON!



! ACTION ! ! ALERT !

NDSC NEEDS ADVOCATES

Sign up for all NDSC Action Alert updates! Scan the QR code.

<https://bit.ly/NDSCActionAlerts>





NDAC Members: NDSC members of all abilities/levels of advocacy experience (anyone can join).

NDAC Group Members: Down syndrome affiliate groups who have opted to join the NDAC program, or other groups (cross-disability, other disability, statewide coalitions).

Scan the QR code to submit an application and join the NDAC Facebook group!

Questions? Email policy@ndsccenter.org



NDAC Statistics

- **1,100 Members** across all 50 states and the District of Columbia
- **131 Self-Advocates** across 42 states and the District of Columbia
- **80 Group Members** across 38 states and multiple countries
- **573 Facebook Members**

Self-Advocate NDAC Members Across the U.S.



Self-Advocates Needed in these States:

- Alaska
- Hawaii
- Maine
- Montana
- New Hampshire
- New Mexico
- Rhode Island
- Vermont

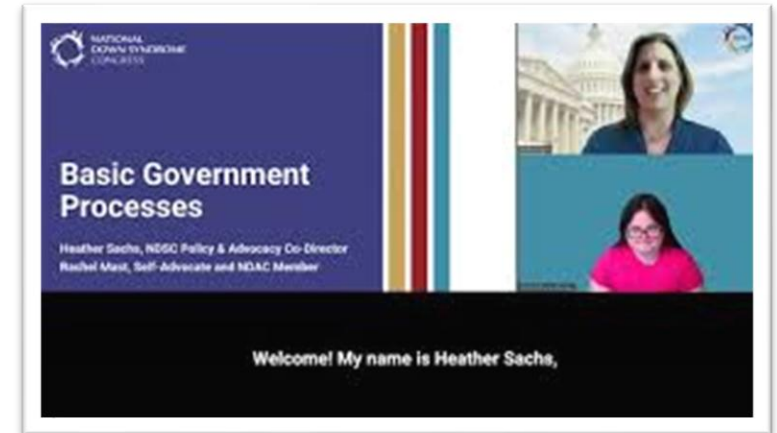
NDAC Goal: Self-Advocate Member in Every State & More Self-Advocate Members in ALL States



NDSC Advocacy Resources

NDSC Advocacy Training & Resources:

- **Self-Advocate (SA) One-Pagers**
 - SA One-Pager Template
 - SA One-Pager Examples
 - Blackburn
 - LaCour
 - Mast
 - Smart
- **Additional Advocacy Resource Documents**
 - Creating an Elevator Speech Template
 - NDSC Advocacy Resource List
 - State Advocacy Engagement Plan
 - Ten Tips for Giving Effective Testimony
 - NDSC Policy & Advocacy Toolkit for Self-Advocates
- **2025 NDSC Advocacy Training Boot Camp Presentations**



Basic Government Processes

[Basic Government Process Video](#)

Basic Government Processes
Slides

NDSC Advocacy Resources

Policy Toolkit for Self-Advocates



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This Toolkit is dedicated in memory of Bruce Bennett, former longtime NDSC Board Member, in appreciation for his generosity and support for NDSC's policy.



[NDSC Policy Advocacy Toolkit for Self-Advocates](#)

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EXCITING NEWS!

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